Rush Alzheimer's Disease Center

Codebook for data set 1219
Generated: 01-04-2023

This codebook contains 16 variables.

Longitudinal cycle explanation

All longitudinal data sets are organized by projid + visit or fu_year

visit	fu_year	explanation
00	0.0	Baseline
01	1.0	1st year follow-up
02	2.0	2nd year follow-up
03	3.0	3rd year follow-up
04	4.0	4th year follow-up
XX	XX.0	XXth year follow-up

variable suffix	type	explanation
_bl	cross-sectional	baseline cycle score; for medical history questions, the score may cover the period from prior to study participation to baseline visit.
_ever	cross-sectional	reported in any cycle at least one time
_l	cross-sectional	last cycle score
_lv	cross-sectional	last valid score
_cum	longitudinal	reported in past history or in at least one follow-up cycle up to this cycle

Clinical Diagnosis

cpd

Clinical Parkinson's Disease

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                                clinical Parkinson's disease


value
0    clinical PD not present
1    self-report history of PD including L-dopa treatment at any time prior to death
     Baseline (parks and medicate = YES), FU (parksfu and medicafu = YES)



table1
value   coding
  1     Yes
  2     Suspect or possible
  3     No
  8     REFUSAL (blaise code)
  9     DON'T KNOW (blaise code)

Baseline
variable   coding    question
parks      table1    Have you been told by a doctor, nurse or therapist that you had
                        PARKINSONISM or PARKINSON S DISEASE?
medicate   table1    Are you currently taking any medication for your parkinsonism or Parkinson s
                        disease (some examples are Sinemet, Symmetrel, Parlodel, Bromocriptine,etc.)

Follow-up
variable   coding    question
parksfu    table1    Since your last evaluation on (MM-DD-YYYY), have you been told by a doctor,
                        nurse or therapist that you had PARKINSONISM or PARKINSON S DISEASE?
medicafu   table1    Are you currently taking any medication for your parkinsonism or Parkinson s
                        disease (some examples are Sinemet, Symmetrel, Parlodel, Bromocriptine,etc.)
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Other Forms : _l, _lv, _bl, _ever

Clinical Diagnosis > Final consensus diagnosis

Final consensus cognitive diagnosis : cogdx

Clinical consensus diagnosis of cognitive status at time of death

Physician’s overall cognitive diagnostic category

At the time of death, all available clinical data were reviewed by a neurologist with expertise in dementia, and a summary diagnostic opinion was rendered regarding the most likely clinical diagnosis at the time of death. Summary diagnoses were made blinded to all postmortem data. Case conferences including one or more neurologists and a neuropsychologist were used for consensus on selected cases.

Value	Coding
1	NCI: No cognitive impairment (No impaired domains)
2	MCI: Mild cognitive impairment (One impaired domain) and NO other cause of CI
3	MCI: Mild cognitive impairment (One impaired domain) AND another cause of CI
4	AD: Alzheimer’s dementia and NO other cause of CI (NINCDS PROB AD)
5	AD: Alzheimer’s dementia AND another cause of CI (NINCDS POSS AD)
6	Other dementia: Other primary cause of dementia

References

Mixed brain pathologies account for most dementia cases in community-dwelling older persons.
Schneider JA, Arvanitakis Z, Bang W, Bennett DA
Journal: Neurology 2007 Dec 11; 69(24) 2197-204

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dxpark

Final Clinical Dx - Hx of Parkinson's disease/Parkinsonism

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                                At the time of death, all available clinical data were reviewed by a
neurologist with expertise in dementia, and a summary diagnostic opinion
was rendered regarding the most likely clinical diagnosis at the time of
death. Summary diagnoses were made blinded to all postmortem data. Case
conferences including one or more neurologists and a neuropsychologist
were used for consensus on selected cases.

This rating is done independent of dementia rating. Also see: "cogdx" variable.


    Did participant have a clinical diagnosis of parkinsonism or
      Parkinson s disease?

       value   coding
        1      Yes
        2      No
        8      REFUSAL
        9      DON'T KNOW
```

References

Mixed brain pathologies account for most dementia cases in community-dwelling older persons.
Schneider JA, Arvanitakis Z, Bang W, Bennett DA
Journal: Neurology 2007 Dec 11; 69(24) 2197-204

Demographics

Age at death : age_death

Age at death

Age of death is calculated from subtracting date of birth from date of death and dividing the difference by days per year (365.25).

For participants in autopsy cohorts, the exact date of death is known for most participants as it is the day an autopsy was performed. In all cohorts, in addition to annual evaluations, participants are also contacted quarterly to determine vital status and changes in health, and death is occasionally learned of during quarterly contacts.

Education : educ

Years of education

The **years of education** variable is based on the number of years of regular school reported at baseline cognitive testing.

References

Education modifies the association of amyloid but not tangles with cognitive function.
Bennett DA, Schneider JA, Wilson RS, Bienias JL, Arnold SE
Journal: Neurology 2005 Sep 27; 65(6) 953-5

Sex : msex

Sex

Self-reported **sex**, with “1” indicating male sex.

Allowable codes
1 = Male
0 = Female

Race : race7

Racial group

As of 10/16/2018, the race variable was updated to reflect the revised NIH categories. Please use this variable in

place of the old race variable (race).

Race is based on self-report at baseline using the following question:

What is your race?

Value	Coding
1	White
2	Black or African American
3	American Indian or Alaska Native
4	Native Hawaiian or Other Pacific Islander
5	Asian
6	Other
7	Unknown

Spanish ethnicity : spanish

Spanish/Hispanic/Latino origin

Are you of **Spanish**/Hispanic/Latino origin?

value	coding
1	Yes
2	No

Pathology

Pathology > Alzheimer's disease

NIA-Reagan diagnosis of AD (dichotomous) : ad_reagan

Presence of AD based on NIA-Reagan diagnosis criteria - dichotomous

This variable is the **dichotomized version of the modified NIA-Reagan diagnosis of Alzheimer's disease**. The criteria rely on both neurofibrillary tangles (Braak) and neuritic plaques (CERAD). See NIA-Reagan diagnosis of AD - 4 levels (/radc/var/displayVariable.htm?id=213) for more information.

Value	Coding
1	AD present by NIA-Reagan pathology criteria (high or intermediate likelihood)
0	AD not present by NIA-Reagan pathology criteria (low likelihood or no AD)

Braak stage : braaksc

Semiquantitative measure of neurofibrillary tangles

Braak Stage is a semiquantitative measure of severity of neurofibrillary tangle (NFT) pathology. Bielschowsky silver stain was used to visualize NFTs in the frontal, temporal, parietal, entorhinal cortex, and the hippocampus. Braak stages were based upon the distribution and severity of NFT pathology:

Braak stages I and II indicate NFTs confined mainly to the entorhinal region of the brain
Braak stages III and IV indicate involvement of limbic regions such as the hippocampus
Braak stages V and VI indicate moderate to severe neocortical involvement.

Diagnosis includes algorithm and neuropathologist's opinion.

value	coding
0	0
1	I
2	II
3	III
4	IV
5	V
6	VI

References

Neuropathology of older persons without cognitive impairment from two community-based studies.

Bennett DA, Schneider JA, Arvanitakis Z, Kelly JF, Aggarwal NT, Shah RC, Wilson RS
Journal: Neurology 2006 Jun 27; 66(12) 1837-44

Neuropathological staging of Alzheimer-related changes.
Braak H, Braak E
Journal: Acta neuropathologica 1991; 82(4) 239-59

CERAD score : ceradsc

Semiquantitative measure of neuritic plaques

CERAD score is a semiquantitative measure of neuritic plaques. A neuropathologic diagnosis was made of no AD, possible AD, probable AD, or definite AD based on semiquantitative estimates of neuritic plaque density as recommended by the Consortium to Establish a Registry for Alzheimer's Disease (CERAD), modified to be implemented without adjustment for age and clinical diagnosis. A CERAD neuropathologic diagnosis of AD required moderate (probable AD) or frequent neuritic plaques (definite AD) in one or more neocortical regions.

Diagnosis includes algorithm and neuropathologist's opinion, blinded to age and all clinical data.

value	coding	if using a binary variable, recommendation is
1	Definite	yes
2	Probable	yes
3	Possible	no
4	No AD	no

References

Neuropathology of older persons without cognitive impairment from two community-based studies.
Bennett DA, Schneider JA, Arvanitakis Z, Kelly JF, Aggarwal NT, Shah RC, Wilson RS
Journal: Neurology 2006 Jun 27; 66(12) 1837-44

The Consortium to Establish a Registry for Alzheimer's Disease (CERAD). Part II. Standardization of the neuropathologic assessment of Alzheimer's disease.
Mirra SS, Heyman A, McKeel D, Sumi SM, Crain BJ, Brownlee LM, Vogel FS, Hughes JP, van Belle G, Berg L
Journal: Neurology 1991 Apr; 41(4) 479-86

Pathology > Beta-Amyloid

Amyloid : amyloid

Overall amyloid level - Mean of 8 brain regions

Amyloid beta protein identified by molecularly-specific immunohistochemistry and quantified by image analysis. Value is percent area of cortex oocupied by amyloid beta. Mean of amyloid beta score in 8 regions (4 or more regions are needed to calculate).

8 regions used

amyloid_hip - hippocampus
amyloid_ec - entorhinal cortex
amyloid_mf - midfrontal cortex
amyloid_it - inferior temporal
amyloid_ag - angular gyrus
amyloid_calc - calcarine cortex
amyloid_cg - anterior cingulate cortex
amyloid_sf - superior frontal cortex

RADC recommendation: use AMYLSQRT when using as outcome variable in models. (mean of the square-root; has better statistical properties)

Item level variables are available upon request.

References

The relationship between cerebral Alzheimer's disease pathology and odour identification in old age.
Wilson RS, Arnold SE, Schneider JA, Tang Y, Bennett DA
Journal: Journal of neurology, neurosurgery, and psychiatry 2007 Jan; 78(1) 30-5

Pathology > Lewy body/PD

henl_4gp

Nigral Neuronal Loss

substantia nigra - neuronal loss - 4 levels

value	coding
0	None/Rare/Scattered
1	Mild
2	Moderate
3	Severe

A variable HENL_YN is also available for internal use.

Pathology > PHF tau tangles

Tangles : tangles

Tangle density - Mean of 8 brain regions

Neuronal neurofibrillary **tangles** are identified by molecularly specific immunohistochemistry (antibodies to abnormally phosphorylated Tau protein, AT8). Cortical density (per mm2) is determined using systematic sampling. Mean of tangle score in 8 regions (4 or more regions are needed to calculate).

8 regions used

tangles_hip - hippocampus
tangles_ec - entorhinal cortex
tangles_mf - midfrontal cortex
tangles_it - inferior temporal
tangles_ag - angular gyrus
tangles_calc - calcarine cortex
tangles_cg - anterior cingulate cortex
tangles_sf - superior frontal cortex

Item level variables are available upon request.

References

The relationship between cerebral Alzheimer's disease pathology and odour identification in old age.
Wilson RS, Arnold SE, Schneider JA, Tang Y, Bennett DA
Journal: Journal of neurology, neurosurgery, and psychiatry 2007 Jan; 78(1) 30-5

Pathology > Vascular - Infarcts - Semi-quantitative

ci_num3_gct

Cerebral Infarctions - Semi-quantitative - Gross-Chronic-Any Location

Cerebral Infarctions

Gross

Value	Coding
0	No Gross Chronic Infarctions
1	One Gross Chronic Infarction, regardless of location
2	Multiple Gross Chronic Infarctions, regardless of location

Neuropathologic evaluations are performed at Rush, blinded to clinical data, and reviewed by a board-certified neuropathologist. A uniform examination includes assessment for common vascular conditions in aging. Examination for cerebral infarcts documents age (acute/subacute/chronic), size, and location (side and region) of infarcts visible to the naked eye on fixed slabs. All grossly visualized and suspected macroscopic infarcts are dissected for histologic confirmation.

References

Microinfarct pathology, dementia, and cognitive systems.
Arvanitakis Z, Leurgans SE, Barnes LL, Bennett DA, Schneider JA
Journal: Stroke 2011 Mar; 42(3) 722-7

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ci_num3_mct

Cerebral Infarctions - Semi-quantitative - Micro-Chronic-Any Location

Cerebral Infarctions

Micro

Value	Coding
0	No Micro Chronic Infarctions
1	One Micro Chronic Infarction, regardless of location
2	Multiple Micro Chronic Infarctions, regardless of location

Neuropathologic evaluations are performed at Rush, blinded to clinical data, and reviewed by a board-certified neuropathologist. A uniform examination includes assessment for common vascular conditions in aging. Examination for cerebral infarcts documents age (acute/subacute/chronic), size, and location (side and region) of infarcts visible to the naked eye on fixed slabs. All grossly visualized and suspected macroscopic infarcts are dissected for histologic confirmation.

A minimum of nine regions in one hemisphere are examined for microinfarcts on 6µm paraffin-embedded sections, stained with hematoxylin/eosin. We examine six cortical regions (midfrontal, middle temporal, entorhinal, hippocampal, inferior parietal, and anterior cingulate cortices), two subcortical regions (anterior basal ganglia, thalamus), and midbrain. Age (acute/subacute/chronic) and location (side and region) of microinfarcts are recorded.

References

Microinfarct pathology, dementia, and cognitive systems.
Arvanitakis Z, Leurgans SE, Barnes LL, Bennett DA, Schneider JA
Journal: Stroke 2011 Mar; 42(3) 722-7